

SUPPLEMENTAL TABLES AND FIGURES

Figure 1. Patient Learner Interview Guide

Part 1. Understanding the Impact of Neuropsychiatric Sequelae

1. What prompted you to watch this program on PBA?
2. If respondent mentions that they or a family member have a neuropsychological condition (e.g., AD, ALS, MS, PD, stroke, TBI), ask: How long have you (or family member) had this condition?
3. How long have you or family member had PBA (or other sequelae such as agitation)?
4. How did you learn that you had PBA (or other sequelae such as agitation)?
5. Before your diagnosis, what kind of symptoms did you have/what prompted you to see an HCP?
6. What did you know about this condition before you/family member were diagnosed?
 - a. What do you think causes PBA?
7. How would you describe PBA to others?
8. What did your HCP tell you about PBA? [prompt for information about resources, support, treatment]
9. What do you know now after seeing this program that would have been helpful to know when you were diagnosed?
10. What would you share with people struggling to understand what's happening to them when they get PBA episodes?
11. What should patients ask their HCPs when they have just been diagnosed with PBA?

Part 2: Treatment

1. What medications are you able to take to help you manage PBA? [probe for: tricyclic antidepressants, SSRIs (e.g., prozac, celexa, luvox), Nuedexta]
2. [If any]: Could you describe what your HCP told you about these medications?
3. How did you think these medications would help you? [speaks to goals]
4. Did you feel you knew what the side effects of these medication might be?
5. What concerns you most about treatment for PBA? [probe for: expectations about treatment, concern about medication side effects or cost]
6. What are some of the things you learned about treatment from the program?
7. What questions would you ask your provider about treatment for PBA after watching the program?

Part 3: Self-Care and Education Needs

1. What are some of the challenges for you in living with PBA? [probe for: relationships? ability to work/get a job? social activities?]
2. What do you find helpful in managing or coping with PBA?
3. Did watching the program provide ideas about what you can do to manage PBA? [probe for: avoiding or leaving social situations, telling people about PBA, thought redirection, relaxation techniques, activity/movement]
4. What tips about managing PBA can you share for other people with PBA?
5. How does your healthcare provider help you cope with PBA?
6. What kind of support do you find helpful in managing PBA?
 - a. Where do you get this support from?
7. What new information did you learn from the program?

Supplementary Table 1. Reported New Self-Care Strategies

Movement/Distracton	Relaxation
Moving position	Take deep breaths, remain calm
Reposition	Learn to relax and breathe
Move in a different position	Take a yoga class or learn more about meditation
Moving, stepping	Remain calm
Removing yourself from situations	Take a deep breath and relax and move
Move your position	Wipe the tears from your eyes and try to think about something else, get your mind in a different framework
Distracton	

Supplementary Table 2. Improvements in Patient/Caregiver Knowledge

Knowledge Questions	Percentage change from baseline to immediate posttest	Relative change from baseline to 8-week follow-up
Goals of PBA treatment	18% ↑ (p < 0.001; d = 1.226)	35% ↑ (p = 0.146; d = 0.476)
Strategies to live more comfortably with PBA	161% ↑ (p = 0.111; d = 0.254)	107% ↑ (p = 0.065; d = 0.524)
Treatment options for PBA	111% ↑ (p = 0.004; d = 0.464)	44% ↑ (p = 0.227; d = 0.347)
Facts regarding PBA episodes	11% ↑ (p = 0.016; d = 0.340)	1% ↓ (p = 0.453; d = 0.235)

We compared matched pair responses with the McNemar test (those who completed pre/post and pre/8wk). Effect size was computed using Cohen's d (small $\geq .20$, medium $\geq .50$, large $\geq .80$). Significance testing was conducted for matched pairs of learners who completed both pre/post and pre/survey, respectively.

Supplementary Table 3. Questions Patients Should Ask their Physicians at Diagnosis

<i>Can they can take DM/Q for PBA? Is there any chance that I have gotten to where I don't need the DM/Q? How would I know? What would I do to find out?</i>
<i>What are my treatment options? Will this subside or go away? Is it pointing to something more serious, or is this just it?</i>
<i>What can we do to live with this better so that I don't have to feel helpless? What different types of medication can you take and what are the side effects? How long can I take it before it before you reach a tolerance level where it's not effective anymore? What types of things can I do to live with it better? What symptoms can I expect so I'm not scared?</i>
<i>Is there medication? What if it doesn't work? Or are there things that you can do when it's happening to lessen the intensity?</i>
<i>Are there programs out there that help with the cost?</i>
<i>Is it basically normal for me to deal with this?</i>
<i>What should the caregiver do? How often should patients come back in [for follow-up]? Is there like an evaluation thing? If I find it happening more or less, do I need to repeat that, like to primary care? Should I keep a journal? Is there medication, or does Zoloft help?</i>
<i>How can we treat this? What's the chance of this going away? What can I do when these things happen to try to lessen the impact of them?</i>
<i>How can you keep the patient calm?</i>

Supplementary Table 4. Tips to Share with Others

<i>It's not their fault, that it's something they can't control</i>

<i>I would tell them to try the moving, you know, stepping thing. And I would tell them it's just something that you're going to have to deal with. it is embarrassing, but you will figure out ways to make it less embarrassing and less noticeable.</i>
<i>That trying to break it, so to speak, when it's first coming on by changing focus or movement. At least for me that was very beneficial. I'd tell them to talk to as many physicians as they can, get as much information as they can. Don't believe just one person.</i>
<i>First of all, it's not a mental – it's not a mental – it's not a mental health issue. It's physical. So, it can be controlled usually by breathing exercises, or sometimes, you know, medication.</i>
<i>It will happen, and to just relax when it happens too...know that it's okay, it happens, and you need to be able to talk about it to your caregiver, your doctor, or just the people around you so that you don't get more upset. Relaxation helps and not being embarrassed. Being able to talk – if it's an ongoing problem, to get rid of that baggage because you have enough problems to begin with.</i>
<i>The main thing I would want them to understand is that it's not them.</i>
<i>Don't be alarmed. If they're diagnosed, understand, read up on it so you understand what they're going through.</i>
<i>It's not a psychological thing. It's a neurological thing, and I think that helped, because crying is seen culturally as a bit of a weakness or too much emotionality or something. So, it's embarrassing, you know? But if you can say, "This is a medical condition. This is neurological, and this isn't me just being weepy," whatever, I think that's important to get across.</i>
<i>Just that it happens. It gets a little better with time. I still have it. It will be five years next month, six weeks or whatever.</i>
<i>I tell them this is normal, this is a normal process for some disease. It's not a normal situation, but it is a condition and maybe there's something we can do. Don't confuse it with the depression and the bipolar. Don't use that medication, because it doesn't work.</i>